

Developing Tools for Needs Assessment for Children in Sub-Saharan Africa: The validation and Application of the PaedsQ4 and NEC Tools in the Zambian Paediatric Population

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Abstract

Introduction: Though significant advances have been achieved in the provision of palliative care in Africa in recent years, there is very little evidence for outcomes of effectiveness of this care. A primary reason for this dearth of evidence is the lack of appropriate and validated outcome tools

Methodology: This study assessed and applied 2 research tools to assess palliative care needs in children attending University teaching hospital in Lusaka, Zambia. The study population was parents and guardians of children receiving care at the university teaching hospital. Sample size was calculated as 100. Trained research assistants approached potential participants and explained the research to them. Following informed voluntary consent the two questionnaires were administered by the research assistants. These were the Needs Evaluations questionnaire (NEQ) and the paedQL4 questionnaires. We used Cronbach's alpha to determine validity and factor analysis to identify relevant factors. We compared the mean difference across the three groups of patients, general paediatric patients, children with HIV, paediatric and oncology patients using ANOVA.

Results: Both tools were found to be reliable for assessing palliative care needs in children (Cronbach's alpha >0.8). Generally there were very high need gaps across all hospital wards with 15/23 items having need gap of >50%. Overall the largest need caps was in information domain. The HIV ward had least need gap with only 8/23 items having a need gap of >50%. Results from the paedQL4 showed that there were significant mean differences across the three categories of patients in all domains of functioning with oncology patients performing worst. In physical functioning domain, the items showed that 6/7 items had significant mean differences ($p < 0.05$). Confirmatory factors analysis showed that 2 items were loading highly on the physical functioning factor. These were running and participating in sports (0.896). In the emotional functioning domain, 2 items loaded highly on factor analysis, feeling sad (0.842 and angry (0.666). In the social functioning domain, highest loading were in 2 items, both related to making friends i.e getting along with friends (0.826) and friend wanting to be friend (0.847). In the school domain missing school to go hospital loaded highly on factor analysis (0.842) followed by difficulty paying attention in class (0.716)

Conclusion: The study successfully applied two quantitative tools for assessing needs in Children. The results showed that the tools are reliable and applicable in the Zambian context. The findings indicate needs gap for child palliative care services in Zambia. Pain control remained in sub-optimal for especially for children with cancer.

Keywords: Pediatric; Palliative care; Logo therapy

Introduction

Palliative Care is the care of people who have been diagnosed with a life threatening or chronic illness. It includes the relief of suffering and management of pain and other symptoms. According to World Health Organization (WHO), palliative care should be an integral part of comprehensive care and support given as part of a continuum of care from the time the incurable disease is diagnosed until the end of life [1].

In Africa, Palliative Care is looked at from the continent's diverse needs, especially in Sub-Saharan Africa, where poverty is rampant and the components of Palliative Care include; practical care, pain and symptom management, emotional support, clean water, income

generation, nutritional support, shelter and spiritual care make. These make a difference in improving the quality of life for thousands suffering from life-threatening illnesses such as HIV and Cancer [2-5].

Significant advances have been achieved in the provision of palliative care in Africa to manage prevalent and burdensome problems experienced by those with incurable terminal disease [6]. However, there is very little evidence for outcomes of effectiveness of this care, a common problem in developing country contexts, where health systems research is under-funded [6,7]. A primary reason for this dearth of evidence is the lack of appropriate and validated outcome tools [7,8]. Advanced care clinicians in Africa identified the need for appropriate outcome tools [10], and suggested that these tools should be appropriate for both HIV and cancer paediatric patients, address family and patient outcomes, be locally validated [11], and be relevant to all stages of the disease trajectory [12]. In addition to

validity and reliability, key principles of outcome tools are brevity and multidimensionality, i.e. addressing physical, emotional, spiritual and social problems of both patients and families. Self-completion tools are often inappropriate for patients with advanced illness, and may not be feasible in populations with limited literacy [2,7,9].

The statement underlines the need for well-designed and validated tools to measure children's outcomes that assessment is the most important aspect of delivering children's palliative care. The measurement of pain and symptoms must be conducted using methods recognizing those children's experiences and expressions of pain and symptoms mediated by age, experience, family, and culture. A study conducted in Uganda identified that skills to communicate with children were the greatest need among palliative care health professionals and the lack of standardised tools to measure palliative care needs in children compounded the challenging task of providing age appropriate and culturally acceptable paediatric palliative care.

The needs evaluation questionnaire

The PaedsQL4 (Pediatric Quality of Life Inventory) (Children's Hospital and Health Center, San Diego, California) is a modular instrument for measuring health-related quality of life (HRQOL) in children and adolescents ages 2 to 18. The PaedsQL4 Generic Core Scales are multidimensional child self-report and parent proxy-report scales developed as the generic core measure to be integrated with the PaedsQL4 Disease-Specific Modules and consists of 23 items applicable for healthy school and community populations, as well as paediatric populations with acute and chronic health conditions. Pediatric patients' self-report of health-related quality of life (HRQOL) has emerged as an important patient-based health outcome. A practical, validated generic measure of HRQOL facilitates assessing risk, tracking health status, and measuring treatment outcomes in paediatric populations [10,11].

This tool has mainly been used in high-income countries. No study has validated this tool in Sub-Saharan Africa where the contexts and palliative care needs for children are said to be complex especially in view of high poverty levels, HIV and poor health systems. In view of the urgent need to develop culturally appropriate tools to accelerate the provision of quality palliative care in Africa, we adopted and adapted the PaedsQ4 inventory and tested it among HIV infected, cancer and children in the general paediatric wards.

Methodology

Study design

This was a cross-sectional study. Both qualitative and quantitative methods were used to collect information. This paper reports quantitative results while qualitative results have been reported in a separate publication.

Study site

The study was conducted at the University teaching hospital in Lusaka which is the main referral hospital in Zambia.

Target population

Parents/ and legal guardians of HIV infected children or children with other chronic diseases attending ART or Oncology clinics, OPD or admitted to the general ward.

Children and youth eligibility

Children were recruited if they were less than 15 years and their parents/guardians had consented to taking part in the study. Eligible children were those with either with HIV or any other Chronic Disease at the time of data collection.

Sample size calculations for quantitative study

The total sample size required for both cancer and HIV patients was 100 guardians/child pair giving an overall of number of participants of 200. The sample size calculation was based on the following assumptions: Power of 80% and confidence level of 95%. The number of children with cancer was 300 the number of children on ART was 500 in 2012. Assuming the proportion of those with palliative care need to be 50% and worse expected to be 40% in each group.

Needs Evaluation Questionnaire was another quantitative tool which we applied to calculate the needs gap. This is a standard and validated rapid tool for needs as expressed by legal guardians on behalf of their children.

Data collection: recruiting participants and administering the questionnaires

All eligible participants were approached by the research team. The voluntary nature of the study was emphasised. They were assured of confidentiality. If they agreed to take part a consent form was given to them to read in the presence of the research team. Children were given an opportunity to know about the purpose of the study and why their parents/legal guardians had been approached to take part the age of the child was taken into consideration when providing information.

PaedsQL4 tool

We used to the PaedsQL4 tool to collect information from guardians with sick children. This is a standard rapid and valid tool for paediatric needs assessment from a point of legal guardians. The categories assessed include, physical, emotional, social and school functioning

Needs Evaluation Questionnaire (NEQ): This is a standard and validated rapid tool for needs as expressed by legal guardians on behalf of their children. This tool was used to collect information from parents and legal guardians of children with cancer or HIV or general paediatric conditions.

Data analysis

Needs gap analysis: We calculated the needs gap by subtracting the % of those which said "Yes" to requiring a particular need out of 23 items from those who said "No". i.e Needs gap=(Yes%-No%).

We compared means across the three groups of patients using ANOVA with $p < 0.05$ indicating a significant difference

Factor analysis: We performed confirmatory factor analysis to determine the factors loading of the items in the NEQ and PaedsQL4 tool. The rotational method applied was Varimax with Kaiser Normalization. Items were retained if they had a co-efficient > 0.5 .

Results

Part 1: Demographic characteristics of children whose parents accepted to take part in the study

There were 109 children/guardian pair participants. Most children were from the HIV ward (71) followed by Oncology (20) and General Ward (18). There were 54% male children and 46% were female (Table 1).

Ward	Sex of Child		
	Male n(%)	Female n(%)	Total n(%)
Oncology	15(75.0)	5(25.0)	20(100.0)
HIV	37(52.1)	34(47.9)	71(100.0)
General	7(38.9)	11(61.1)	18(100.0)
Total	59(54.1)	50(45.9)	109(100.0)

Table 1: Sex distribution of participants stratified by ward.

Age group (years)	Sex of Child		
	Male n(%)	Female n(%)	Total n(%)
<1 year	6(46.2)	7(53.8)	13(100.0)
1-5 years	21(48.8)	22(51.2)	43(100.0)
6-10 years	22(62.9)	13(37.1)	35(100.0)
11-16 years	10(55.6)	8(44.4)	18(100.0)
Total	59(54.1)	50(45.9)	109(100.0)

Table 2: Age distribution of children of participating parents.

Need items	Needs Gap (%YES-% NO)			
	Total	Oncology	HIV	General
1 "I need more information about the child's diagnosis"	63.4	65.3	60.6	67
2 "I need more information about my child's future condition"	70.3*	90*	63.4*	72.6*
3 "I need more information about the examination done to my child"	54.2	50	52.2	66.6
4 "I need more explanations about the child's treatments"	59.6	50	52.2	100*
5 "I need to be more involved in the therapeutic choices of my child"	50.4	80*	40.8	55.6
6 "I need clinicians and nurses to give me more comprehensible information"	56	70	43.6	88.8*
7 "I need clinicians to be more sincere with me about the child's illness"	47.6	60	40.8	66.6
8 "I need to have a better dialogue with clinicians"	59.1	70*	52.2	77.8*
9 "I need the child's symptoms (pain, nausea, insomnia, etc.) to be better controlled"	52.4	50	46.4	77.8*
10 "The child needs more help with eating, dressing, and going to the bathroom"	-7.4	50	-29.6	22.2
11 "I need better respect for our privacy"	52.2	-20	15.4	33.4
12 "I need better attention from nurses"	52.2	70	46.4	55.6

The age ranged from 0-16 years standard deviation 4.175. Mean age was 5.74. In terms of age distribution most participating children were aged 1-5 (43/109: 48.8% male and 52.2% Female) (Table 2). Most participants were the child's mother (69.7%), with 13.8% of fathers and 16.5% other relatives (Table 3).

Valid	Frequency	Percent	Valid Percent	Cumulative Percent
Male	18	16.5	16.5	16.5
Female	91	83.5	83.5	100
Total	109	100	100	-

Table 3: Sex distribution of guardian/parent.

Part 2: Reliability and applicability of the needs assessment (NEQ) tool

Generally there were very high needs Gaps across all hospital wards with 15/23 items having needs gap of >50%.

Overall the largest needs caps was in information domain. The item related to information about future prognosis (needs gap 70.3). The second highest overall needs gap were in item related to need for economic support. When wards were compared oncology ward 20/23 items had a needs gap of >50%. Higher needs gaps were noted in information about prognosis, and in economic support (need gap 90%). In the general ward, 19/23 item had needs gap >50%. The highest needs gap of 100% was noted in information about the treatment given to children.

The HIV ward had least needs gap with only 8/23 items having a needs gap of >50%. In this group information about future prognosis again had highest needs gap (63.4%) (Table 4).

13	"I need to be more reassured by the clinicians"	37.6	50	29.6	55.4
14	"I need better services from the hospital (bathrooms, meals, cleaning)"	26.6	80	1.4	71.6
15	"I need to have more economic-insurance information (tickets, in relation to my illness"	54.2	50	60.6	88.8*
16	"I need economic help in caring for my child"	63.5	90*	55	66.6*
17	"The child needs to see a psychologist our counsellor "	48.6	80*	38	55.6
18	"The child needs to see a spiritual counsellor or priest"	52.2	0	35.2	88.8*
19	"Child needs to speak with people who have this same experience"	46.8	85*	32.4	55.6
20	"I need to be more reassured by my relatives"	35.8	60	26.8	44.4
21	"I need to feel more useful within my family"	50.4	70*	40.8	66.6*
22	"I need to feel less abandoned"	26.6	40	19.4	43.4
23	"I need to receive less commiseration from other people"	-12	0	-24	22.2

Cronbach's alpha for the 23 items was 0.874 (>0.7).

Notes: Needs Gap =Y-N: It was calculated as proportion of who say Yes(Y) minus proportion of those who said no(N) to each item

Table 4: Needs Gap analysis for the 23 needs items.

The highest factor loading were in Information domain. Information about: Examination (0.852), treatment (0.832) and prognosis (0.769). Other factors which loaded highly were, need for spiritual help (0.909), need for economic assistance (0.842) and psychosocial support (0.854) (Table 5).

	Components						
	Physical	Information	Communication	Economic	Psychosocial	Spiritual	Relational
I need more information about the child's diagnosis		0.697					
I need more information about my child's future condition		0.769					
I need more information about the examination done to my child		0.852					
I need more explanations about the child's treatments		0.832					
Need to be more involved in therapeutic choices of my child		0.51					
Need clinicians and nurses to give me more comprehensible information			0.735				
Need clinicians to be more sincere about the child's illness			0.729				
I need to have better dialogue with clinicians			0.601				
Need the child's symptoms (e.g.pain) to be better controlled	0.553						
Child needs more help eating, dressing, and going to bathroom	0.625						
I need better respect for our privacy							0.616
I need better attention from nurses							0.525
I need to be more reassured by the clinicians							0.657
I need better services from the hospital (bathrooms, meals etc)							
Need to have more economic-insurance information in relation to my illness				0.842			
I need economic help in caring for my child							

The child needs to see a psychologist our counsellor					0.854		
The child needs to see a spiritual counsellor or priest						0.909	
Child needs to speak with people who have this same experience							
I need to be more reassured by my relatives							0.67
I need to feel more useful within my family							0.725
I need to feel less abandoned							0.759
I need to receive less commiseration from other people							0.849
Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.							

Table 6: Confirmatory factor analysis for the 23 items for needs assessment.

Part 3: Reliability and applicability of PaedsQ4 needs assessment tool

Out of the 109 children, 64 attended school while the rest did not attend. Among all the children represented the highest mean score was noted in pain and aches (Mean 1.28, std deviation 1.248, feeling angry

(mean 1.12 std deviation 1.192). For the 64 patients who attended school, the highest mean scores was in missing schools to attend clinics (mean 1.91, std deviation 1.080) and missing school because of feeling unwell (mean 1.62 std deviation 1.162) (Table 6).

	N	Minimum	Maximum	Mean	Std. Deviation
Walking few meters (5-10 m)	109	0	4	0.8	1.332
Running	109	0	4	0.91	1.405
Participating in sports activity or exercises	109	0	4	0.9	1.453
Lifting something heavy	109	0	4	0.9	1.44
Doing chores (e.g. Picking up toys/helping at home)	109	0	4	0.85	1.339
Having hurts/aches or pain	109	0	4	1.28	1.248
Feeling afraid or scared	109	0	4	0.96	1.217
Feeling sad	109	0	4	0.99	1.243
Feeling angry	109	0	4	1.12	1.192
Trouble sleeping	109	0	4	0.54	1.076
Worrying about what will happen to him or her	109	0	4	0.73	1.16
Getting along with other children	109	0	4	0.74	1.279
Other children wanting to be his or her friend	109	0	4	0.83	1.325
Getting teased by other children	109	0	4	0.65	1.075
Not able to do things that other children same age do	109	0	4	0.98	1.408
Keeping up when playing with other children	109	0	4	0.9	1.312
Paying attention in class	64	0	4	0.92	1.337
Forgetting things	64	0	4	0.88	1.134
Keeping up with school work	64	0	4	1.09	1.377
Missing school because of not feeling well	64	0	4	1.62	1.162

Missing school to go to the doctor or hospital	64	0	4	1.91	1.08
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Table 6: PaedsQ4 assessments: Descriptive statistics for children admitted to UTH children, in Lusaka.

Cronbach's test was used to assess the reliability of the 21 items that make up the paedQL4. The results were separated for those items applicable to all (16 items) and those only applied to children attending school (5 items). Cronbach's alpha for the 16 items which applied to all

children was 0.903 which is considered very reliable. Reliability for the 5 items which assessed school functioning gave a Cronbach's alpha of 0.744 (Table 7).

Group	n	Number of items	Cronbach's Alpha
All participants	109	16	0.903
Children attending school	64	5	0.744
Oncology	20	16	0.882
HIV ward	71	16	0.893
General	18	16	0.897

Note: Cronbach's alpha >0.7 is considered reliable

Table 7: Reliability test for the paedQL4 assessment tool.

Reliability test was done for the three wards to see if there was a difference in the reliability of the paedQL4 in assessing patients with different problems. ie. Oncology, HIV and general paediatric problems. Cronbach's alpha was 0.882 for oncology patients, 0.893 for HIV patients and 0.897 for patients with general paediatric problems.

Table 8 shows that there were significant mean differences across the three categories of patients in all domains of functioning with oncology patients performing worst.

Physical functioning			Sum of Squares	Df	Mean Square	F	Sig.
Walking few metres(5-10 m) * WARD	Between Groups	(Combined)	17.064	2	8.532	5.183	0.007
	Within Groups		174.496	106	1.646		
Running * WARD	Between Groups	(Combined)	35.276	2	17.638	10.515	0
	Within Groups		177.806	106	1.677		
Participating in sports activity or exercises * WARD	Between Groups	(Combined)	25.988	2	12.994	6.822	0.002
	Within Groups		201.902	106	1.905		
Lifting something heavy * WARD	Between Groups	(Combined)	31.979	2	15.99	8.832	0
	Within Groups		191.911	106	1.81		
Doing chores(e.g. Picking up toys/helping at home) * WARD	Between Groups	(Combined)	2.991	2	1.496	0.832	0.438
	Within Groups		190.66	106	1.799		
Having hurts/aches or pain * WARD	Between Groups	(Combined)	12.308	2	6.154	4.185	0.018
	Within Groups		155.876	106	1.471		
Emotional Functioning							
Feeling afraid or scared * WARD	Between Groups	(Combined)	7.164	2	3.582	2.487	0.088
	Within Groups		152.689	106	1.44		
Feeling sad * WARD	Between Groups	(Combined)	6.727	2	3.363	2.225	0.113
	Within Groups		160.264	106	1.512		

Feeling angry * WARD	Between Groups	(Combined)	2.206	2	1.103	0.773	0.464
	Within Groups		151.244	106	1.427		
Trouble sleeping * WARD	Between Groups	(Combined)	18.22	2	9.11	9.038	0
	Within Groups		106.844	106	1.008		
Worrying about what will happen to him or her * WARD	Between Groups	(Combined)	16.228	2	8.114	6.664	0.002
	Within Groups		129.056	106	1.218		
Social Functioning							
Getting along with other children * WARD	Between Groups	(Combined)	8.03	2	4.015	2.522	0.085
	Within Groups		168.777	106	1.592		
Other children wanting to be his or her friend * WARD	Between Groups	(Combined)	11.78	2	5.89	3.509	0.033
	Within Groups		177.908	106	1.678		
Getting teased by other children * WARD	Between Groups	(Combined)	1.76	2	0.88	0.758	0.471
	Within Groups		122.993	106	1.16		
Not able to do things that other children his/ her age can do * WARD	Between Groups	(Combined)	20.848	2	10.424	5.722	0.004
	Within Groups		193.115	106	1.822		
Keeping up when playing with other children * WARD	Between Groups	(Combined)	14.341	2	7.17	4.431	0.014
	Within Groups		171.549	106	1.618		
School Functioning							
Paying attention in class * WARD	Between Groups	(Combined)	6.423	2	3.211	1.845	0.167
	Within Groups		106.187	61	1.741		
Forgetting things * WARD	Between Groups	(Combined)	9.043	2	4.522	3.833	0.027
	Within Groups		71.957	61	1.18		
Keeping up with school work * WARD	Between Groups	(Combined)	5.91	2	2.955	1.588	0.213
	Within Groups		113.527	61	1.861		
Missing school because of not feeling well * WARD	Between Groups	(Combined)	9.468	2	4.734	3.823	0.027
	Within Groups		75.532	61	1.238		
Missing school to go to the doctor or hospital * WARD	Between Groups	(Combined)	5.066	2	2.533	2.26	0.113
	Within Groups		68.372	61	1.121		

Table 8: ANOVA Comparing the mean between the three groups of parents in general, Oncology and HIV units.

Confirmatory factors analysis showed that 2 items were loading highly on the physical functioning factor. These were running and participating in sports (0.896). In the emotional functioning domain, 2 items loaded highly on factor analysis, feeling sad (0.842 and angry (0.666). In the social functioning domain, highest loading were in 2

items, both related to making friends i.e getting along with friends (0.826) and friend wanting to be friend (0.847). In the school domain missing school to go to hospital loaded highly on factor analysis (0.842) followed by difficulty paying attention in class (0.716) (Table 9).

	Physical	Emotional	Social	School
Walking few metres(5-10 m)	0.765			
Running	0.896			

Participating in sports activity or exercises	0.896			
Lifting something heavy	0.715			
Doing chores(e.g. Picking up toys/helping at home)	0.484			
Feeling afraid or scared		0.592		
Feeling sad		0.842		
Feeling angry		0.666		
Trouble sleeping		0.298		
Worrying about what will happen to him or her		0.106		
Getting along with other children			0.826	
Other children wanting to be his or her friend			0.847	
Getting teased by other children			0.484	
Not able to do things that other children			0.571	
Keeping up when playing with other children			0.573	
Paying attention in class				0.716
Forgetting things				0.625
Keeping up with school work				0.643
Missing school because of not feeling well				0.707
Missing school to go to the doctor or hospital				0.842

Table 9: Confirmatory Factor analysis for the 21 items making up the paedics Q4 tool.

Discussion

One challenge reported in the literature which prevent adequate provision of palliative care needs is the lack of validated tools for assessing palliative care needs especially among children [12-14]. Our study tested and applied two known tools for assessing palliative care needs in children. The tools tested were the paedicsLQ4 and the Needs Evaluation Questionnaire (NEQ). The results showed that the paedicsLQ4 and the NEQ needs assessment tools are applicable in the Zambian paediatric population. The reliability tests for both tools showed Cronbach's alpha of over 0.8. We therefore were confident to apply these tools to assess the needs for three different paediatric population seeking cancer, HIV and general paediatric services at the University teaching hospital in Lusaka, Zambia.

At the time of this study, the first African paediatric version of the APCA African Palliative Outcome Scale was still undergoing validation [15].

Generally, there were significant palliative care needs gaps with 15 of the specific needs assessed revealing a need gap of over 50%. This was based on the needs assessment questionnaire (NEQ) which has previous been applied to adult patients but has never been applied in children or low-income settings [16]. The tool was found to be fairly reliable with Cronbach's alpha of 0.874.

Overall the largest need gap was in information domain. Information especially about the long-term outcomes of children's illness was very important to parents and guardians. They wanted to know about what would happen to their children in the future with

respect to the prognosis. Similar findings have been reported in other studies which have shown that sincere discussions about the future prognosis was a major need for families and patients [17]. The second highest overall need gap was in economic support domain. These findings agree with other studies conducted in Sub-Saharan Africa which have shown that palliative care in these settings cannot be separated from socio-economic challenges that families face [6,18].

In terms of symptoms management, pain remained the highest unmet need for children admitted to the University teaching hospital. These findings were supported by the qualitative study findings where most parents expressed concern that their children were receiving in adequate pain relief (result reported elsewhere). This problem was more pronounced among children with cancer, but it is of note that children on the general ward also reported inadequate pain relief. Other studies have also reported that pain management is a big challenge in sub-Saharan Africa [15,19]. This has been attributed to inadequate knowledge on pain management by clinicians and inhibitory laws that prevent access to morphine [15,19]. This might be true for Zambia where palliative care training is not routinely taught to clinicians and restrictive laws prevent wide access to morphine.

Missing school was one issue that was raised by most families. For children admitted or needing to attend clinics, they missed a lot of classes and this was affecting their performance. This need has not been adequately addressed as classes for those admitted are not routinely offered and those attending clinics were given dates which conflicted with their school calendar.

In this study we also used the paedLQ4 questionnaire which has been used in high income countries to assess needs among children [11]. Our results showed that this tool is applicable in the Zambian context. The tool was reliable with the Cronbach's alpha for the 16 item of 0.903.

When we compared the three groups of patients i.e. oncology, HIV and general ward using the paedLQ4, we found significant mean differences across these three categories of patients in all domains of functioning.

We performed a confirmatory factors analysis to identify items with higher loading from the paedLQ4 tool. Results showed that two items loaded highly on the physical functioning factor. These were running and participating in sports (0.896). These findings support the need for pain control and enabling environment for children to play even when they are unwell. Playing is an important part of child growth [20]. Our qualitative results also confirmed the lack of recreation activities for children admitted to the University teaching hospital in Lusaka.

The emotional functioning domain, showed that one item loaded highly on factor analysis, (feeling sad, coefficient=0.842). This finding point to the need for psychological support not only for families but children as well.

The World Health Organization (WHO) pioneered a Public Health Strategy for integrating palliative care into a country's health care system. This strategy include advice and guidelines on how governments can priorities and implement both national palliative care programs and national cancer control programs where palliative care is one of the four key pillars of comprehensive cancer control [21]. Zambia could benefit from adopting this approach in view of the gaps identified in this study, which require integration and coordination of palliative care services.

The study has a number of limitations that must be considered when interpreting the study results. Firstly the study was a cross-sectional survey hence we cannot determine causality based on these results. Secondly, the study was done in the urban settings, the findings may not apply in rural settings. Thirdly the study was done at the University Teaching Hospital which is the main referral centre and hence the sample might not be representative of palliative care needs in the general population.

Conclusion

This study applied two quantitative tools for assessing palliative care needs in Children. The results showed that the tools were fairly reliable and applicable in the Zambian urban context but further validation is required for rural settings. The findings indicate a significant needs gap for children's palliative care services in Zambia. The major family needs were economic and bereavement support. There was high demand for information for families, which health workers did not adequately provide. Pain control remained sub-optimal especially for children with cancer. The findings indicate huge needs gap for child palliative care services.

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